South Carolina Department of Disabilities and Special Needs
Pervasive Developmental Disorder (PDD) Program
March 2013

Number of Children

- 1,526 children have received PDD services since the program's inception
- 770 children are currently participating in the PDD Program
  (587 enrolled in the waiver and 183 in state-funded slots)
- 986 children are on the waiting list
- 266 new slots (in addition to attrition) were authorized since July 1, 2012
- Approximately 82% of all participants are male and 18% are female
- Approximately 88% of all participants have a diagnosis of autism and 12% have other PDD diagnoses
- Approximately 73% of participants are ages 3-6; 25% are ages 7-10

Utilization of Services/Resources

- The proviso caps expenditures for each individual child at $50,000 per year
- The average budget DDSN authorized for each child based on the individual assessment and service plan is $32,567 per year
- Increased the number of qualified providers to 21 companies and over 47 consultants; began with three companies and five consultants
- Improved coordination with First Steps to transition BabyNet children. This prevents disruption of services. 48 children have transitioned since October 2012.
- 80% of children are Medicaid eligible

Funding

$7.5M	Original appropriated amount
$6.975M	Current appropriated base
$6.006M	Actual expenditures for FY2012
$6.425M	Projected expenditures for FY2013. Note: DDSN had requested a rate increase for direct line therapists in FY2011. It was anticipated this would be approved and expended in FY2012 and FY2013.

Services

Children accepted in the Pervasive Developmental Disorder (PDD) Program receive two types of services:

1) Early Intensive Behavioral Intervention (EIBI) and
2) Case Management.

EIBI services seek to develop skills of children in the areas of cognition, behavior, communication and social interaction. Case management services assist children and their families in gaining access to needed waiver and other State Medicaid plan services, as well as medical, social, educational and other services.

Program Improvements

1. Award state-funded slots to children prior to Medicaid eligibility determination. This allows the family to complete paperwork, the child to be assessed, the plan developed and the start of therapy before completion of Medicaid eligibility process. If the child is determined Medicaid eligible, funding is shifted from 100 percent state to PDD waiver.

2. Allow children younger than three years of age to apply for PDD services. If eligible, the child may be placed on the waiting list. Children are not enrolled in the Program until after they turn three but this prevents time delay.

3. Implemented new process to increase utilization of authorized budget by families. This includes better education of families about the program and family responsibility. By working with families at the beginning, it can be more realistically determined how much time the family can commit to a therapy schedule.

4. More frequently monitor family utilization of services and adjust hours and corresponding budget up or down accordingly. This method is still responsive to the needs of the individual child but also prevents over-authorization of state funds.

5. Changed timing of provider payment to improve timeliness of service delivery. Previously DDSN paid provider once the assessment and service plan were completed. Now full payment is withheld until the provider completes these and trains direct-line therapists, decreasing time delay before actual services begin.

6. Began providing learning supplies and tools for families receiving EIBI to enhance their children's outcomes.

7. Collaborate with the SC Autism Society and the Developmental Disabilities Council to ensure that parents of children on the PDD waiting list have a clear understanding of what the PDD Program provides, how it works, and the family's commitment.

8. Through its contract with the University of Nevada's Distant Education program, DDSN graduated its second set of students in December 2011 taking five graduate-level courses approved by the National Board of Applied Behavior Analysis to prepare them for Board Certification. This will increase the capacity of approved providers of DDSN's PDD program.

9. Developed and began a quality assurance review of EIBI providers to ensure high quality of services.

10. Finalized contract language in partnership with DHHS for EIBI providers that focuses on the provider delivering a minimum level of the authorized intervention hours. This helps DDSN ensure budgets are closer to utilization.

11. DDSN collaborates with USC's Department of Psychology. At no charge, the Department assists DDSN and its network of EIBI providers to develop the direct-line therapists who do the majority of the in-home interventions with children and their families. DDSN is now targeting Winthrop, Francis Marion and Coastal Carolina universities to replicate USC's model.

12. DDSN collaborated with USC's College of Social Work. At no charge, the College conducted an evaluation of DDSN's PDD program focusing on results, parent satisfaction, and family indicators that lead to better outcomes.

13. Recruited qualified Board-certified Behavior Analysts (BCBA) attending the National Association of Behavioral Analysts annual meeting June 2011.

<u>New Initiatives</u>

1. Submitted a formal request for approval of a rate increase in 2011 for direct-line therapists (not provider overhead) to meet the need to recruit and retain the necessary number of individuals who work directly with the children. At least one direct-line therapist is needed for each child/family. CMS approval was received February 7, 2013.

2. Contracting with a professional recruiting company to recruit, screen, and conduct background checks on potentially qualified line therapists; the line therapists are the people who spend the most time with the child and family implementing the plan prepared by the BCBA. 122 hired since November 2011.

3. Coordinating policy efforts with First Steps. DDSN created a smooth transition for children diagnosed with a Pervasive Developmental Disorder (PDD) receiving Early Intensive Behavioral Intervention (EIBI) services through the BabyNet program to move seamlessly into the PDD Program. As these children age out of BabyNet services at age 3, individualized EIBI services through the PDD Program continue essential interventions which improve children's skills. The result eliminated a gap in services and improved the children's outcome measures. 48 have transitioned since October 2012.

4. Developed and distributed the PDD Parent Handbook which is available online and hard copy in both English and Spanish. This new handbook informs parents about the Pervasive Developmental Disorder Program. It describes the specialized services and options parents have to manage and maximize their child's services, including their role in assuring the best possible outcomes are achieved. The result is increased consumer information, increased involvement of parents in their children's treatment, and increased consumer control over who provides the services.

5. Developed and issued a third RFP for graduate level training courses to increase the number of Board Certified Behavior Analysts specifically for children participating in the Pervasive Developmental Disorder (PDD) Program and people participating in the Intellectual Disabilities/Related Disabilities Waiver and the Traumatic Brain Injury and Spinal Cord Injury Waiver. One result is a more cost-effective approach to training a core group of students than the typical university enrollment process and fees. Another result is thirty-five (35) students enrolled in the training with a commitment to provide services for a minimum of two years in exchange for tuition costs.

6. In December 2012, DDSN requested that USC conduct another, more comprehensive study of the PDD program to determine if children participating in the program continue to show improvement across all measures of functioning [areas of adaptive functioning (eating , bathing, dressing, toileting), expressive and receptive communication (speaking, understanding what others are saying to them, and learning), socialization (playing with peers, being able to grocery shop with mom) and cognitive functioning (learning, staying on par with peers.)]

   Due to the richness of available data, DDSN is uniquely positioned to advance knowledge regarding the predictors of positive outcomes associated with this program. These results will provide important additional insights for the delivery of treatment services at DDSN and for the broader understanding of treatment policy for children with autism.

   This new study will include about 500 more children and families and will specifically aim to:

   1. Evaluate the impact of PDD services on child outcomes (cognitive functioning, adaptive functioning and verbal ability)

   2. Assess the child-specific factors associated with differences in outcomes (attributes of children who are most likely to experience positive outcomes)

   3. Explore the relationship between the changes in adaptive behaviors through time and the actual treatment hours received (how differences in treatment hours contribute to the positive outcomes)

Outcomes

DDSN operates an evidence-based program for children with Pervasive Developmental Disorders (PDD). The interventions are based on Early Intensive Behavior Intervention (EIBI) and focus on enhancing cognition, communication, adaptive behavior and social skills, all of which are significant issues for children with autism spectrum disorders. DDSN's model is a home-based treatment program that requires parental involvement to ensure the interventions are carried out throughout the child's day.

To date, DDSN has provided EIBI programs to more than 1,400 children ages 3 through 10 years old. The outcomes of these individualized programs are remarkable and mirror the research conducted on programs just like DDSN's program. The majority of children in the PDD program experience statistically significant gains in all areas for which children with autism have severe deficits: expressive communication, receptive communication, adaptive living and use of appropriate social skills.

Expressive communication is what children can say with words or sign language. Many children came into the program unable to speak or used very few meaningful words. Now, the majority of children use words, sign language or picture exchange systems to communicate with peers, teachers and parents. Quotes from a survey of parents of children in the program include, "He is a different child. I would never have imagined that he would respond to a question or initiate conversation with his family or schoolmates." "Please do not take this program away from my child. She is talking! She has made so much progress, and I can't thank you enough for giving my daughter a chance to be like other children." To be able to ask for what one wants or needs or to let a parent or teacher know that they are in pain is a huge milestone for these children. By enhancing Expressive Communication, behavior challenges can be markedly decreased, allowing socially significant behaviors to improve.

Receptive communication is a child's ability to understand, process, and react or respond to the verbal and nonverbal language of others. Growth in this area affects one's ability to follow directions, answer questions, and respond to commands in emergency situations. Being able to follow directions leads to the development of expressive communication skills. Children who received EIBI services for three years showed an average gain of 15% in the area of Receptive Communication.

Daily living skills are being able to care for one's self by learning skills such as toileting, bathing and getting dressed and are extremely important skills for children with a PDD to develop so they can function as independently as possible. The average gain in this area for those who completed three years of service was seven years.

Socialization skills - Many children diagnosed with a PDD do not interact with their family members or typically developing peers in an appropriate manner. The deficiency in language and communication also make it difficult to form personal relationships and friendships. Intensive programming delivered in the child's natural environment enhances their skills and abilities in this area. Children who received three years of EIBI services saw a reliable change of 72%.

Pervasive Developmental Disorder Program Evaluation

Robert Hock, PhD — **USC College of Social Work**
John Kuntz, MS — **USC Department of Epidemiology**

Introduction

During the 2006 legislative session of the South Carolina General Assembly, $3 million was appropriated to the South Carolina Department of Disabilities and Special Needs (DDSN) to develop the Pervasive Developmental Disorder (PDD) Program by January 2007. During the 2007 session, the General Assembly appropriated an additional $4.5 million demonstrating their commitment to the treatment of autism and other PDDs. DDSN uses much of this state funding as match dollars to earn Medicaid federal financial participation.

The purpose of the PDD Program is to provide intensive in-home intervention to children ages 3 through 10 years diagnosed with a Pervasive Developmental Disorder, which includes Autism, Asperger's and PDD – NOS (Not Otherwise Specified). Children who meet these criteria may receive Early Intensive Behavioral Intervention (EIBI) services for three years or until their 11th birthday, whichever comes first.

Early Intensive Behavioral Intervention applies the principles of Applied Behavior Analysis, which is an evidenced-based individualized treatment program for persons with autism. Studies across the country show that the majority of children receiving EIBI services make significant gains in all areas of concern. These areas include cognitive functioning, communication, socialization/daily living skills, and problematic behaviors.

DDSN wanted to evaluate the effectiveness of South Carolina's PDD Program at improving key outcomes for children. They requested an independent analysis from the University of South Carolina, College of Social Work along with the Department of Epidemiology. Dr. Robert Hock and John Kuntz conducted the first evaluation gratuitously, for DDSN.

Following is a report of our findings using valid statistical and analytical models.

Method

Using preliminary data obtained from the South Carolina Department of Disabilities and Special Needs (DDSN), an analysis was conducted to assess children's improvement in several key outcome areas during their participation in Early Intensive Behavioral Intervention (EIBI) as part of the PDD Program. A total of 70 children who had recently completed 3 years of EIBI were included in the analysis. Each child completed an evaluation of his or her social, behavioral and cognitive abilities before treatment began, as well as after the first and second years of treatment.

Analysis

Three research questions guided the analysis.

Do the baseline measurements improve after approximately two years of EIBI treatment?

In order to address this question, two approaches were taken. First, a paired comparison was made between the final and baseline measures for each child. A paired t-test was used to assess whether those differences are statistically significant. In order to determine whether the change

was clinically meaningful, a reliable change index was calculated to determine the proportion of children whose individual scores have changed to an extent that is beyond statistical variability.

Is there evidence that any such improvements are greater than those expected by maturation or the passage of time?

To address this question, we examined differences in baseline scores by the child's age at the beginning of the program. If older children tend to demonstrate higher standard scores than younger children at the beginning of treatment, this may suggest that change occurs with maturation alone. Because the standard scores are computed relative to a child's same age group, higher scores would indicate higher performance relative to other same age peers.

Is there evidence that improvements may vary based on the characteristics of the child?

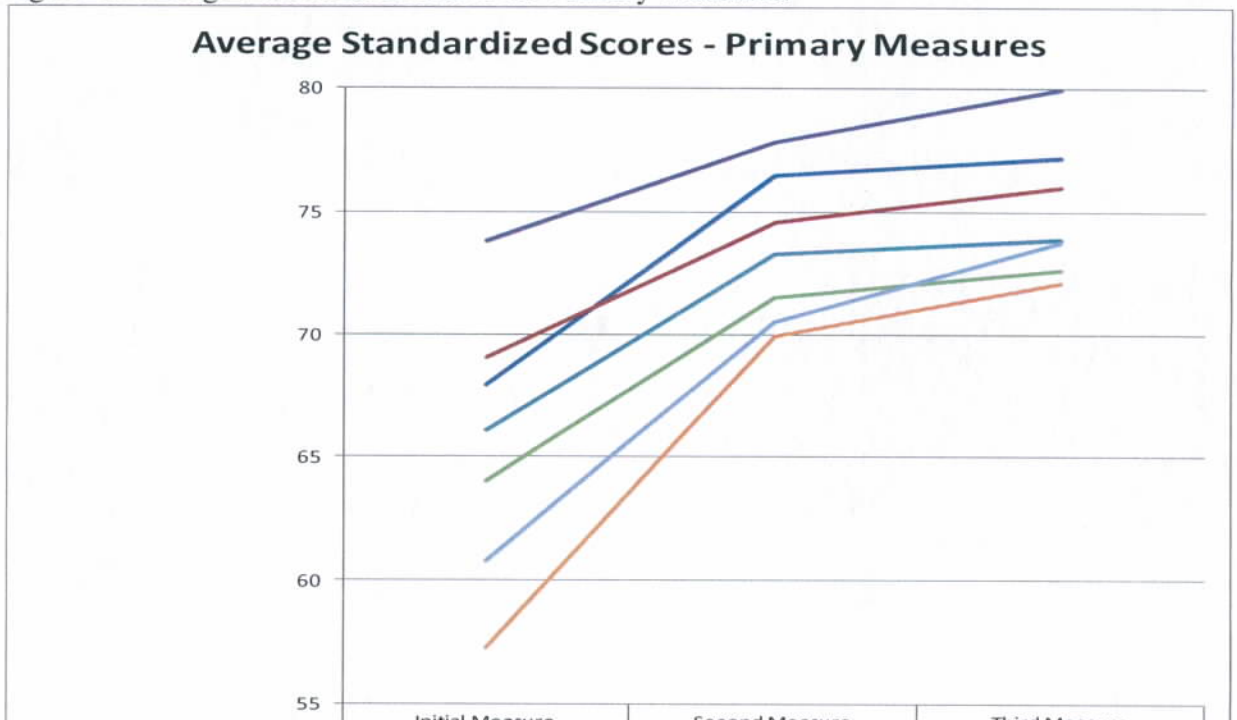
To address this question, we examined whether a child's age or abilities at enrollment predicted their degree of improvement in the program over time.

Results

Do the baseline measurements improve after approximately two years of EIBI treatment?

Results of the paired t-tests comparing the final measure to the initial measure show a statistically significant improvement in all seven primary measures (Figure 1).

Figure 1. Average Standardized scores for Primary Measures.



	Initial Measure	Second Measure	Third Measure
Average Communication	67.95	76.47	77.14
Average DLS	69.04	74.60	76.00
Average Social	64.01	71.51	72.64
Average Motor	73.82	77.81	79.90
Average ABC	66.08	73.26	73.89
Average PPvT	57.28	69.94	72.12
Average EVT	60.79	70.50	73.77

Reliable change is provided as a measure of the proportion of children who experience meaningful change, or a change that is beyond the variation in the baseline measurement. Using the calculated reliable change metric, a significant number of children achieved reliable change across all domains (Figure 3). Motor skills (not an EIBI target area) shows gains in 45% of children while all other measures show reliable gains in more than 50% of the children, with improvements in Communication, Social and Adaptive Behavior Composite (ABC) domains among 70% of the children all of which are EIBI target areas.

Figure 2. Standard scores of key outcome measures at baseline and year 2 of the intervention.

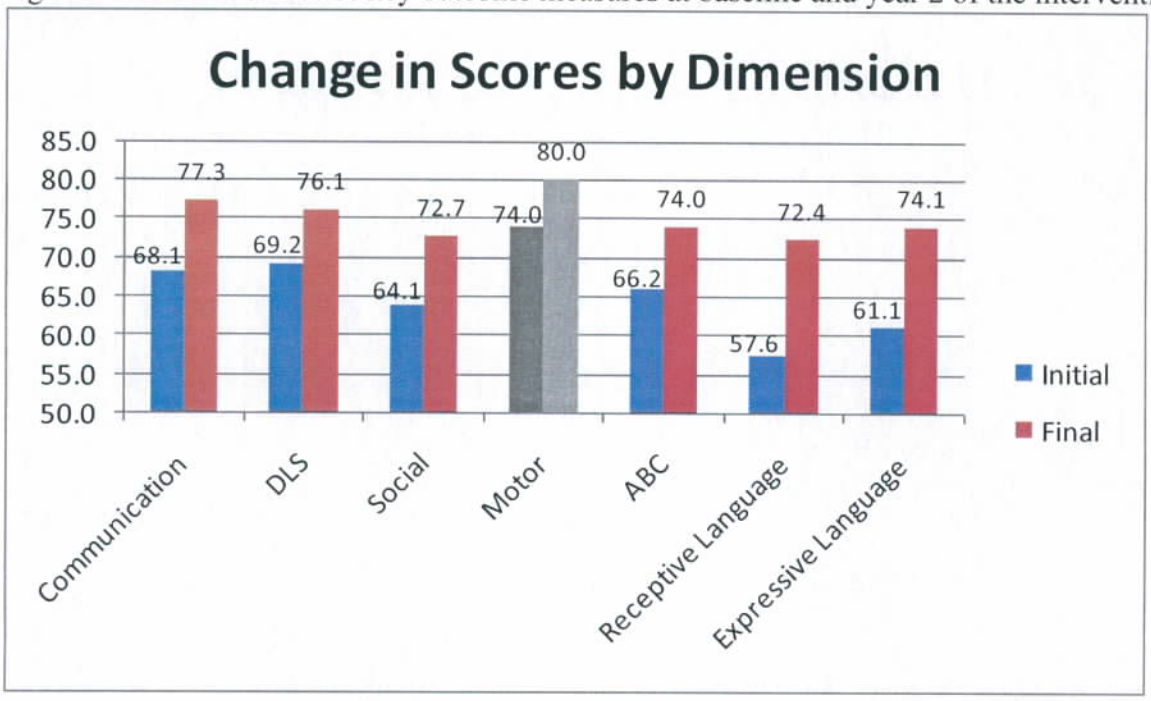
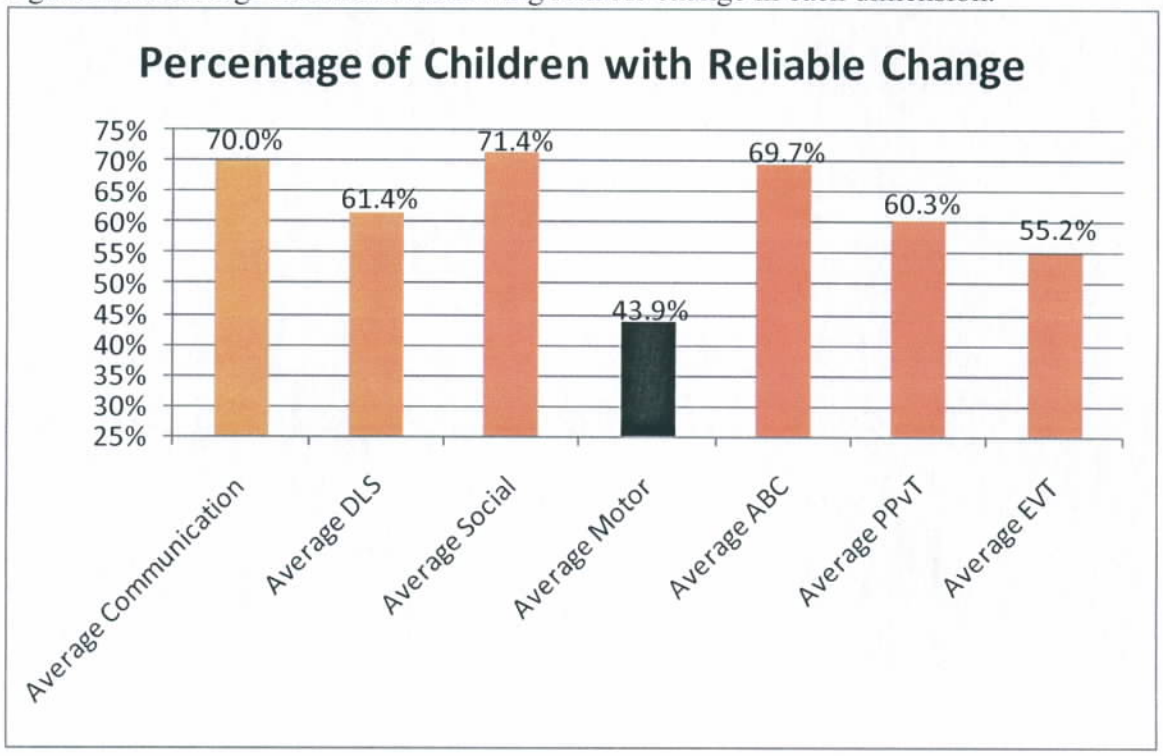


Figure 3. Percentage of children achieving reliable change in each dimension.



Is there evidence that any such improvements are greater than those expected by maturation or the passage of time?

Results indicate that there is no significant relationship between a child's age at entry and his/her baseline scores on any of the outcome measures. This improves confidence that improvements seen over time are due to EIBI treatment and are not the result of normal age-related improvement.

Is there evidence that improvements may vary based on the characteristics of the child?

Two baseline characteristics were considered in examination of differing effects: age at enrollment and overall performance, calculated as the average of the 7 primary measures.

Minimal differences were observed in the significance of the individual t-tests by age group, where age groups were constructed to establish equally-sized categories (less than 4.8 years, 4.8 – 5.8 years and older than 5.8 years at enrollment).

Separate analysis was performed by categories of baseline performance (high, medium, low) based on the average of all scores. Here, some differences in results were observed. Specifically, high performing individuals did not show significant gains in vocabulary and low-performing individuals did not show gains in social skills.

Summary

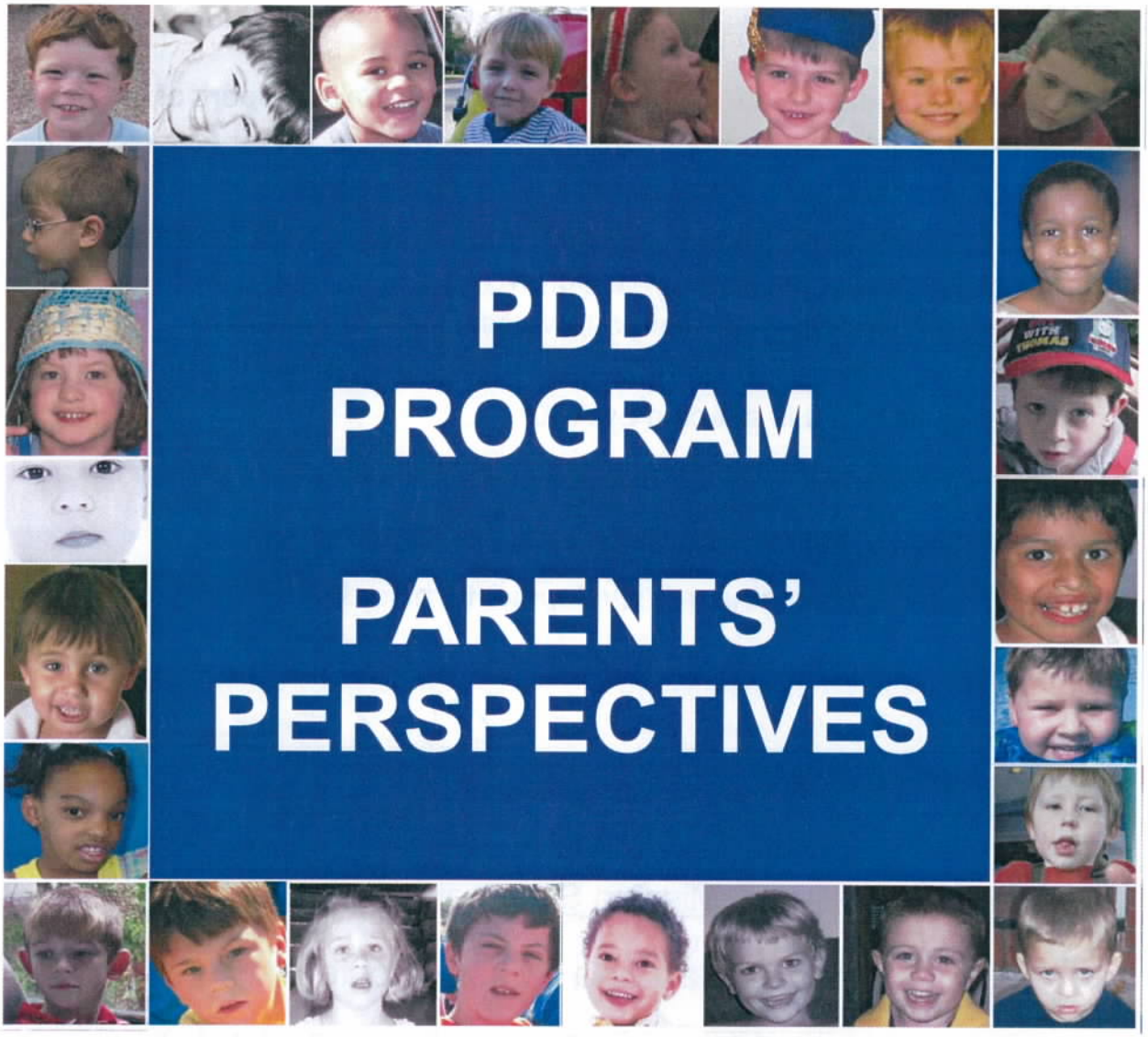
The results of this evaluation suggest the following:

- **Children enrolled in the PDD Program show improvement across all measures of functioning**
- **Within specific domains, approximately 70 percent of children achieve reliable change**
- **Both younger and older children show improvement**
- **There is some evidence that the highest-performing children at baseline show less improvement through time**

These findings are promising and suggest that the PDD Program is increasing the skills and adaptive functioning of children in South Carolina.

South Carolina Autism Society

Together We Can Solve The Puzzle



PDD PROGRAM

PARENTS' PERSPECTIVES

April 2011

The South Carolina Autism Society, a statewide nonprofit advocacy organization, did an informal parent survey through Survey Monkey. Parents and caregivers who have a child currently or who were receiving services through the Pervasive Developmental Program (PDD Program) were asked to provide their perspective on the progress their child has made since being on the program. Questions asked were based on the progress parents observe in the five major domain areas an intensive intervention program addresses.

As a way of thanking you for you for your on going support of the PDD Program, we would like to share with you the parents' perspectives on the benefits of this program. As you will see, the feedback from parents was astounding. We would like to personally thank you for your foresight and support in improving the lives of children with Autism Spectrum Disorders (ASD) in South Carolina. Here are a few basic facts about ASD:

- 1 child in 110 is affected by ASD
- Approximately 41,000 South Carolinians are on the spectrum
- ASD is 4 times more likely to affect boys than a girls
- Fastest growing neuro-developmental disorder

Margie Moore-Willliamson
Parent Liaison

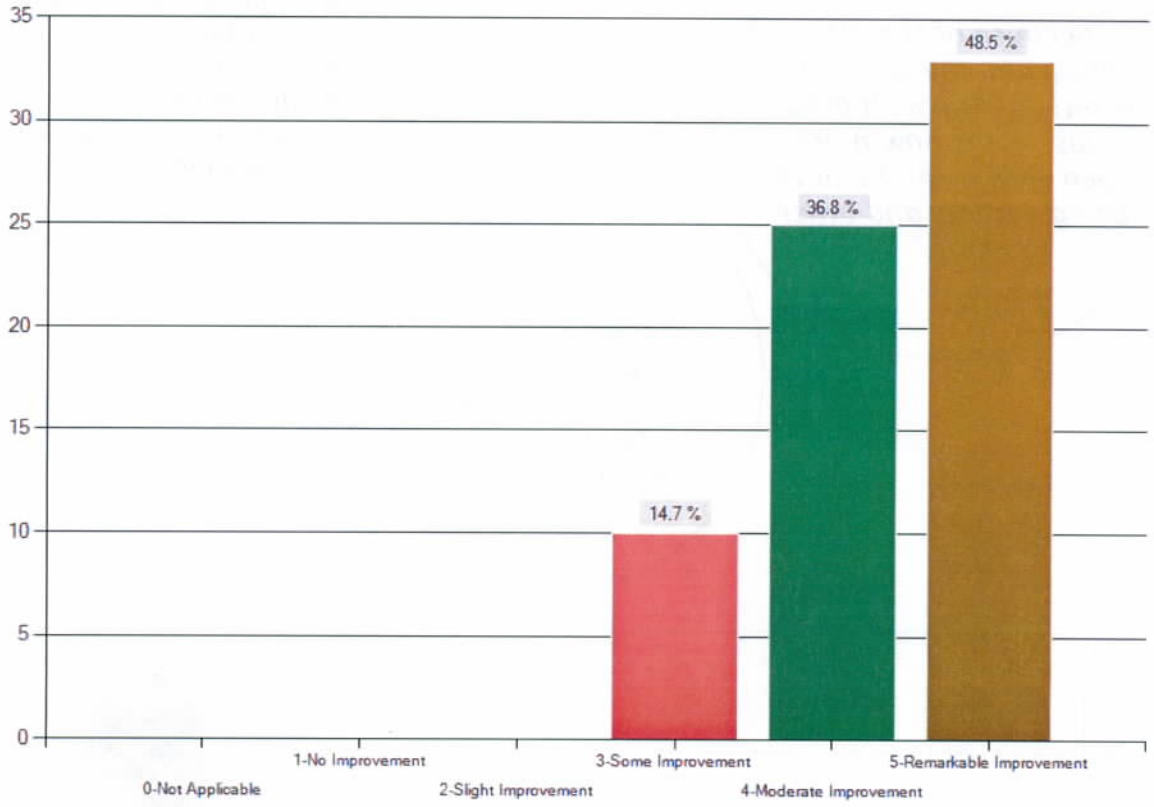
Craig C. Stoxen
President & CEO

Mission Statement

South Carolina Autism Society

The purpose of the South Carolina Autism Society is to enable all individuals with autism spectrum disorders in South Carolina to reach their maximum potential.

1. Rank the improvement you have seen in your child's behavior.



"She was not talking, she was quite aggressive with head banging tendencies, she also was not potty trained prior to ABA therapy which we are now receiving under the PDD Waiver. With the waiver, our ABA therapist helped us learn positive practices for potty training, she has helped her redirect her aggressive tendencies and now has a vocabulary of about 50 words."

"It was impossible to take our child out to eat or any place there was lots of people. Last summer, we went on vacation and he was able to eat in the dining room each night and play appropriately."

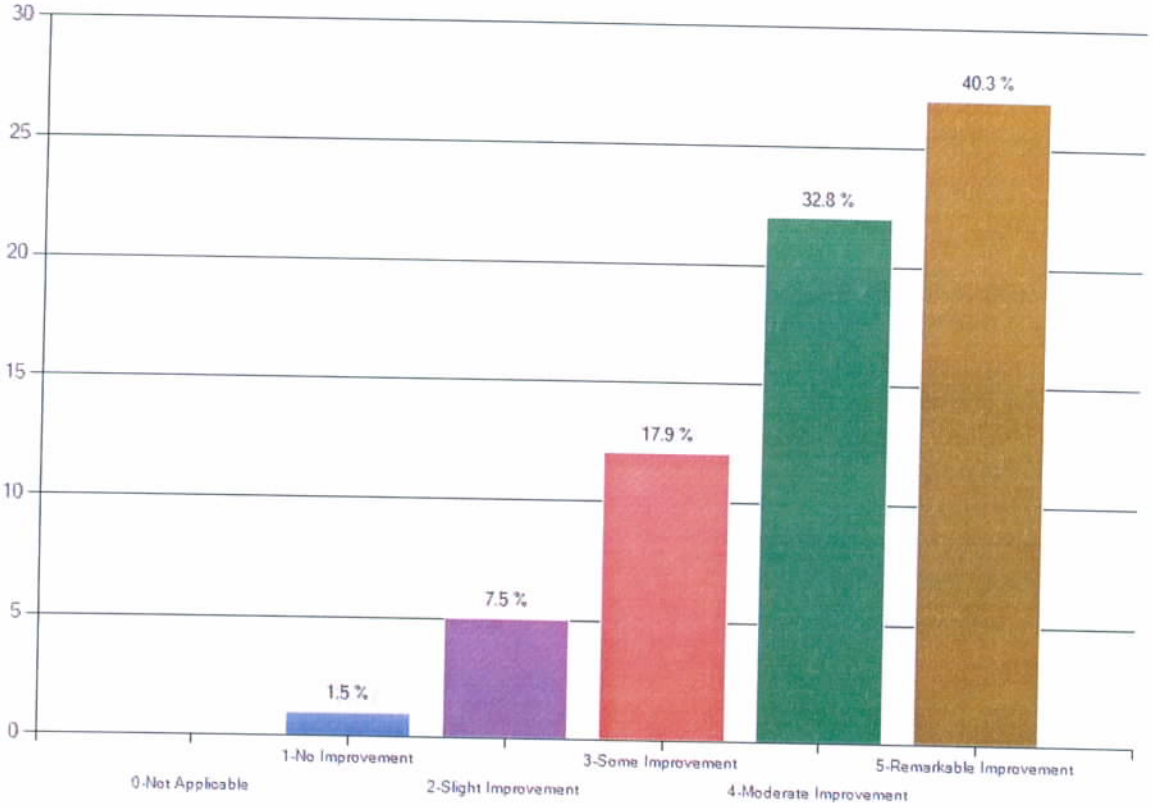
"My child used to hit, bite or get extremely upset. He now uses his acquired language to express himself. He will still get emotional at times, but is not hitting, biting or screaming."

2. Rank the improvement you have seen in your child's social skills.

"Because of the PDD Program, my son now wants to play with other kids. He is now more open with us and enjoys being with us and other kids."

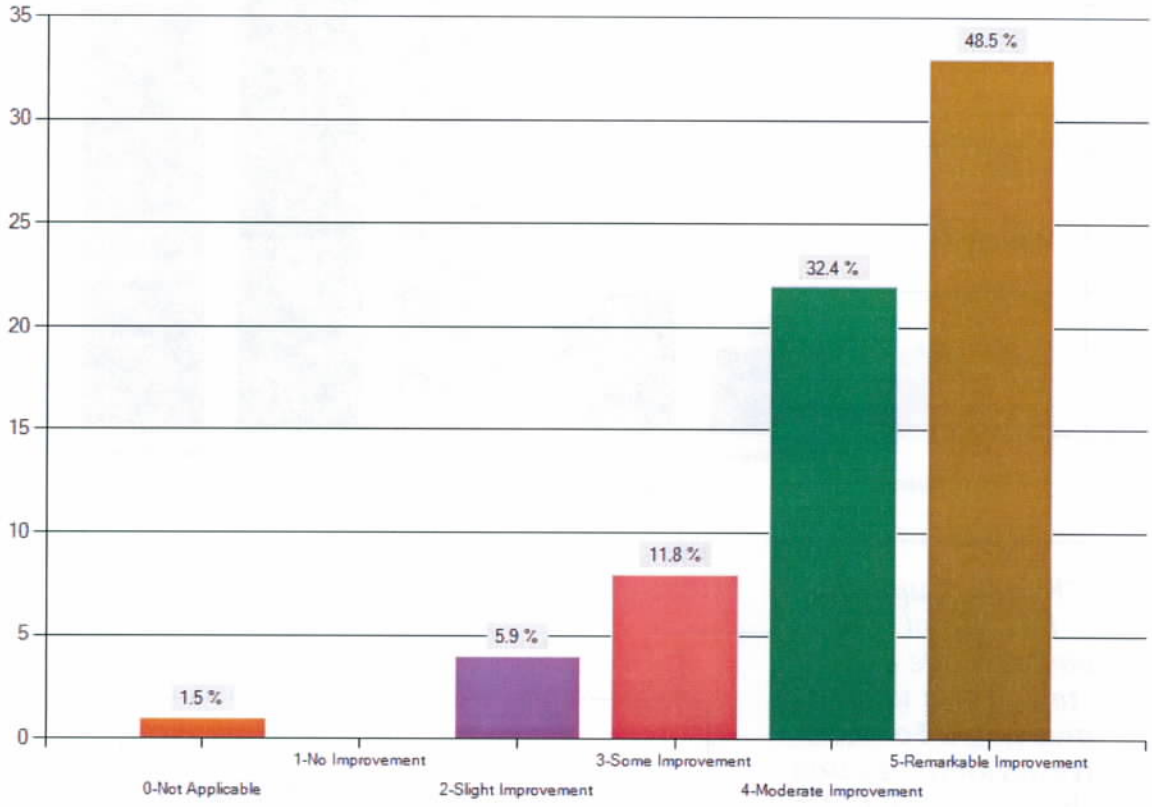
"On a recent outing his therapist was able to prompt him to say hello to a cashier at the grocery store without hiding and having an anxiety attack. That was a great moment for us."

"He is going into regular 1st grade classes for part of the day. Sometimes he doesn't need any help to stay there and interact with kids his age."



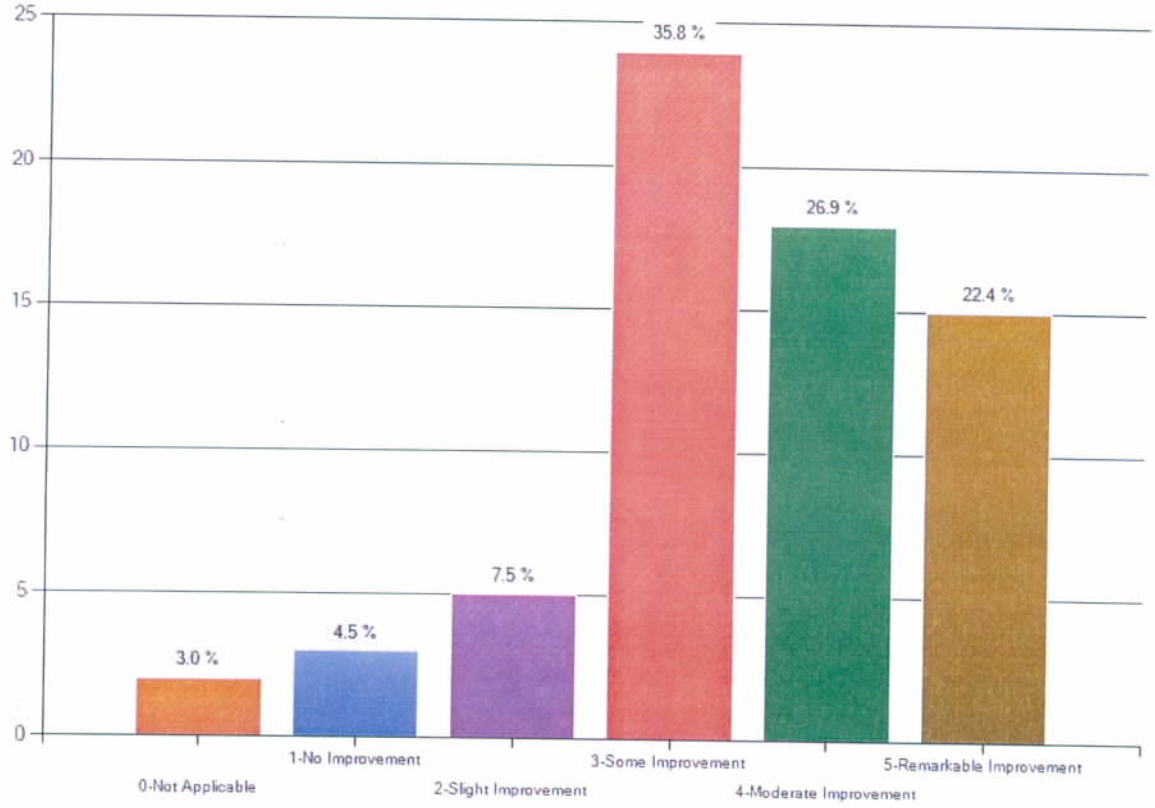
3. Rank the improvement you have seen in your child's functional communication.

"After several years on the PDD program, my child no longer needs speech therapy at this time. His communication skills are wonderful!"



"My son went from saying just a few, one word requests, to now putting short, 4 to 6 word sentences together. He went from only mom understanding his words to a stranger understanding most of what he says."

4. Rank the improvement you have seen in your child's recreational skills.



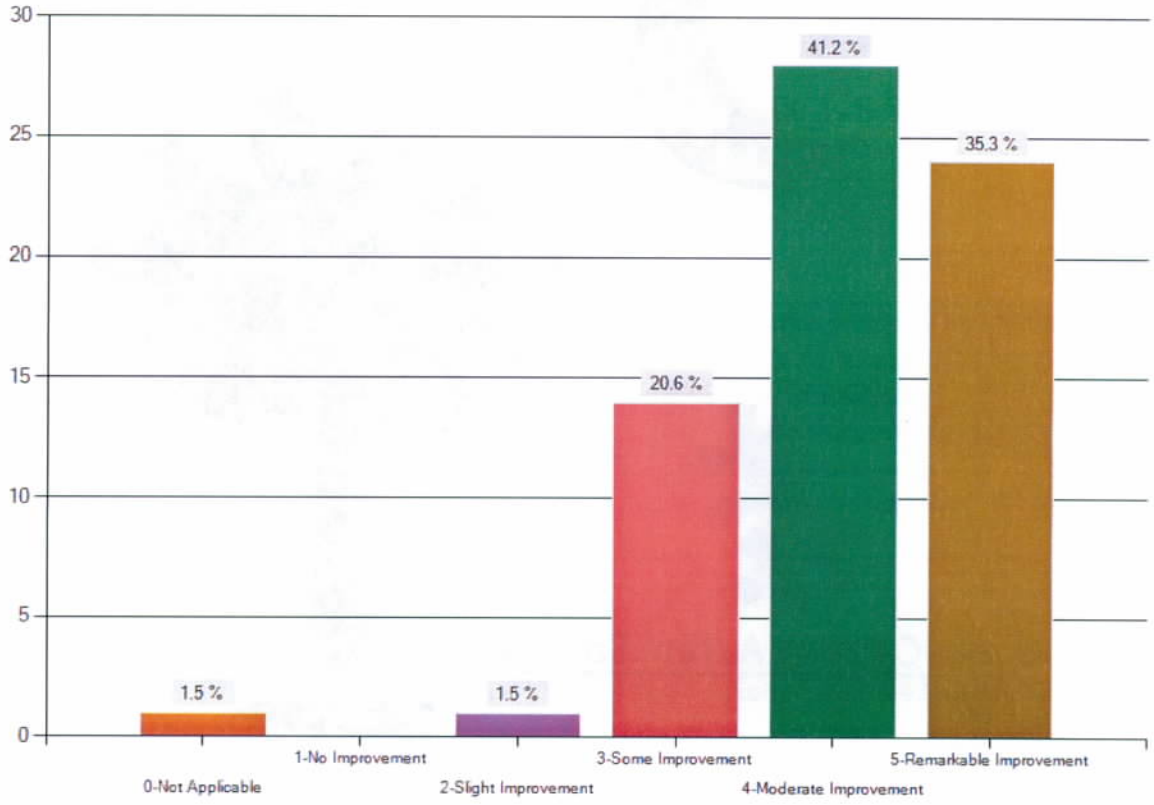
"He plays upward basketball. The pastor made a point to call him up and give him a Southern Wesleyan jersey and the ball in front of a whole gymnasium."

"John now enjoys coloring. I used to give him a piece of candy for coloring even part of a picture. Now he draws, colors, and makes up stories about his play. I remember when he was first diagnosed with Autism 3 years ago, I tried to pretend play with him with some Little People farm figures- he threw the figures, ran from the room, jumped on my bed and flapped furiously in front of the mirror. Now he plays super heroes with his Daddy!"

5. Rank the improvement you have seen in your child's daily living skills.

"My son now sets the table for the family, can get his own drink, can give himself a bath and get his own night clothes. He can pick out his own clothes to wear and they always match."

"Toilet training is almost done!! He is able to brush his teeth really well and change clothes when he chooses. None of these could have been accomplished without the waiver."



"He is now able to tie his own shoes, independently dresses, independently washes & brush teeth with supervision. He cleans up after himself (including toys; this was BIG problem behavior in the past) and now knows the appropriate function of certain things (ex: A spoon is to eat with. Pillow is to sleep with)."

Thanks for your ongoing support!

South Carolina Autism Society

Together We Can Solve The Puzzle

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